

# Alzheimer's Disease: Latino Community

## ***EL PORTAL***

A Dementia Network  
Serving Latinos



Developed by the  
Los Angeles Alzheimer's  
Association and the California  
Department of Health  
Services

**Alzheimer's Disease Demonstration Grants to State Program**

A Program of the U.S. Administration on Aging

Latino Community

## **Why El Portal?**

Of the nine million persons who reside in Los Angeles County, about 36 percent are Hispanic or Latino. The east and southeast sections of Los Angeles County have 54% of California's Latino population and nearly a fifth of the nation's Hispanics. Yet the Latino community in Los Angeles was not being served by the existing dementia programs. There were no dementia specific services targeting Latinos in the geographic area.

## **How El Portal Was Developed**

Initial discussions between state and local providers of aging services had been ongoing for approximately a year and a half prior to the award of an Alzheimer's Demonstration grant. These early discussions helped partners identify their roles and needs. Partners included California Department of Health Services, the Los Angeles Chapter of the Alzheimer's Association (lead agency for the grant), the Department of Mental Health, the Department of Social Services, the Department of Aging and local provider agencies.

## **Building Trust**

For the project to succeed, trust had to be built among the partner agencies and ways had to be found for the partner agencies to work together. All partners had to be honest about the resources they could bring to the partnership, and they had to be honest about the promises they made. It was essential that organizations not promise services or resources they could not deliver.

The need for trust was also evident when the partnership agencies met to discuss continuing the El Portal project beyond federal grant support. This required each partner agency to discuss its own grant funding plans and to collaboratively agree on which foundations would be approached for support for the whole project and which would be most likely to support individual components of El Portal. Without the trust that had been developed among all partners, this level of disclosure would not have been possible and the continuation of El Portal would have been in jeopardy when the HRSA funding ended.

To develop services in the Latino community, providers of dementia services set out to become more familiar with the Latino community on the east and southeast side of Los Angeles. Project meetings were held in the target area to familiarize all partners with the community being served.

One aspect of the program that proved essential to success was the designation of a key staff member from the Department of Mental Health as the Director of the El Portal program. This person spent one day a week in the Los Angeles Alzheimer's Association chapters headquarters. This person is a well-known and respected member of both the Latino community and the service-provider community. This strategic integration of staff provided an effective means for teaching the staff of the Alzheimer's Association and the dementia providers about cultural beliefs and differences within the Latino community. It helped the project gain the trust of the Latino community and gave the project an entrance to the network of mental health providers.

## Community Participation

Initial service efforts focused on educating local professionals and providers about dementia issues. Media were widely used to reach the community. Press conferences were held in the Latino community. Advisory groups were developed for outreach efforts and to help inform the community about dementia. These advisory groups included clergy, representatives from local businesses, caregivers and service providers. Pharmacies agreed to insert El Portal postcards in prescription bags. These postcards allowed potential clients to use a toll free number to ask for more information or for help on specific problems.

El Portal staff provided on-going technical assistance to partners during start-up. Partner agencies hosted educational events for caregivers and the general public. Brochures were developed with full participation of partner agencies and caregivers. Groups met monthly to assess the content and format of the brochure materials. Representatives of six different Spanish-speaking cultural groups in the target area reviewed the materials for clarity.

## Barriers and Obstacles

The initial, critical barriers to partnership were lack of knowledge and awareness. At the beginning of the project there was a general lack of awareness of the extent of dementia in the Latino community. Additionally, there was significant cultural resistance to acknowledging dementia as an illness. Since Latinos were very conscious of privacy issues, dementia was stigmatized in the community. In general, service providers

were not familiar with the Latino community culturally or geographically. Also, because of citizenship issues, some Latinos are apprehensive about government agencies and services. In working with Latino elders without citizenship, eligibility for service from government programs becomes an issue.

## How Service Capacity Was Expanded

Ongoing, supportive technical assistance provided an effective means for increasing service capacity. Training sessions went both directions between El Portal staff and providers. Each side had expertise to offer to the other. The goal was to use the services that existed and enhance them through additional training and communication. For instance, staff identified a need for training on how to work with families at risk for violence and how to identify a potential violent situation where a client might be a danger to self or others. Caregivers were offered training on how to address combative behaviors.

Quarterly audits provided a structure to keep everyone informed about unmet needs and new service needs. Strategic planning and steering committees met regularly to identify and address service issues and how best to support the providers.

In addition to developing services in the Latino community, El Portal has trained Care Advocates to assist Latino elders and their families in accessing available existing services. Care Advocates are bilingual and bicultural and are from the community. Care Advocates sometimes accompany case managers on home visits or go with clients to service agencies.

Care Advocates are also trained to address the family's care needs. They have skills in identifying needs, providing dementia education to caregivers and helping with translation.

### **Program Costs and Generating Additional Funding**

The overall costs for developing El Portal were substantial, given the magnitude and array of services that were newly created and the cost of doing business in Los Angeles. If one looks only at a dollars-to-clients-served ratio, the program may appear costly. But the true outcome of the project is the dementia service network. It is difficult to put a dollar value on such a network. Thus, looking only at the number of clients served is somewhat misleading. Networking, discussion sessions, partner-building activities and trust-building efforts all take time and money before a project can begin to reach an under-served population. These up front costs should be amortized over the life of El Portal.

About one-third of the annual budget was earmarked for respite subsidies to families. The average annual cost per bilingual care advocate was \$50,000. Legal services were approximately \$22,000 per year. Day care centers that offered respite two or three days a week cost \$20,000 per year.

At the midpoint in the grant funding, partner agencies formed a work group to collaborate on maintaining the program after the Alzheimer's Demonstration funds ended. Collaborative grant writing and funding requests have generated \$800,000 so far and other initiatives are currently pending. Additionally, there

are plans to increase the service area to include four more cities. The initial Alzheimer's Demonstration sites are now positioned to receive state funds as the Department of Aging looks to increase the number of day care sites in the area.

### **Keys to Success**

1. Partners had a commitment to serve caregiving families.
2. Partners were willing to examine their own beliefs and cultural misunderstandings.
3. Partners made a commitment to serve and to collaborate.
4. Partners were willing to learn and accept their limitations.
5. Partners viewed the program as a means of building a dementia services network that would ultimately reduce service costs.

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## Latino Community

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